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ABSTRACT

Designed primarily for parents of children with genetic disorders, the booklet provides information about parent groups. Part 1 describes parent groups, including organization, types of groups, and methods of outreach. A sample letter of invitation to attend a parent group and an outline of the initial meeting is included along with a list of three books on the topic of self help organizations. In Part 2, suggested discussion topics are presented and educational, health care, and advocacy activities are described. The final part provides addresses of federal programs working with genetic disorders and organizations concerned with either genetics in general or with a specific condition. (PHR)

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LEARNING TOGETHER

A Guide for Families With Genetic Disorders

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DHEW Publication No. (HSA) 80-5131

U.S. DEPARTMENT OF HEALTH, EDUCATION AND WELFARE
Public Health Service
Health Services Administration
Bureau of Community Health Services
5600 Fishers Lane, Rockville, Md. 20857

PREFACE

"Learning Together" is for people who want and need to work together to solve common problems. It is primarily for parents of children with genetic disorders, but it may help all parents with handicapped or seriously ill children.

Parents can learn together. They can assure better health care, education, and lives for all children. They can help each other and their own families.

"Learning Together" was written by Debra Haffner, M.P.H., Bureau of Community Health Services. Acknowledgment for their comprehensive review of the manuscript is made to Dr. Lowell Levin and Dr. James Jekel, Yale University School of Medicine; Dr. Allen Crocker, Harvard University; Dr. Andrew Lorincz, University of Alabama, Birmingham; Ms. Peg Morton, Montgomery County (Maryland) Association for Retarded Citizens; Ms. Jayne Mackta, National Tay-Sachs and Allied Diseases Association; Dr. Nancy Wexler and Dr. Clarice Reid of the National Institutes of Health; and staff of the Bureau of Community Health Services.

TO PARENTS

Perhaps you have recently had a baby who was born with a genetic disorder. Or you have an older child who may have problems that doctors say are genetic. Or you may have been living with a genetic condition in your family for a long time.

You are not alone. Twelve million Americans have some type of condition. Each year, 210,000 babies are born with genetic disorders or birth defects. One out of three childhood admissions to a hospital is caused by a genetic disorder.

In fact, any couple can have a child with a genetic condition. It is guessed that every person has between five and eight harmful genes. Two to four of every 100 babies have a genetic disorder.

Of course, not all genetic disorders are alike. They are caused by different changes, errors, or combinations of genes and chromosomes. Some disorders affect people only mildly and others cause very serious illnesses and handicaps.

Sometimes, you may feel that your family is the only one that has this type of problem. Actually, millions of families have children with genetic conditions and diseases. They, like you, face the concerns, fears, and challenges of raising a child who has genetically-caused problems.

Many parents find it helpful to meet with other parents who have children with similar problems. These parents either form or join self-help or mutual aid groups. They meet regularly to talk about their feelings and experiences, share ideas, and work out problems. They help each other learn to cope with the difficulties and to live as happy families. They work together to provide the best possible life for themselves and their children.

This booklet will tell you more about parent groups. It can help you decide if you want to join or organize one. Part I contains information on parent groups and tips for organizing a group. Part II suggests activities for the group. Part III lists organizations that will help you.

PART I

PARENT GROUPS

Belonging to a parent group has been very helpful to some parents. You can look for a group in your community to join. You can organize a group if there is not one in your area or an existing organization does not meet your needs.

Why Join A Group?

- To talk to other parents who also have a child with a genetic disorder.
- To get practical help in coping with your situation from other parents who share similar problems.
- To find out where to go for help and information.
- To learn how to obtain the best health care for your child.
- To help other parents.
- To accomplish more than you could alone.

How Do I Find A Group?

Ask your pediatrician or family doctor if there is a local parent or self-help group related to genetic disorders. Look in the telephone book to see if there is a group related to a specific disorder or a chapter of a national organization, such as the March of Dimes Birth Defects Foundation or the Association for Retarded Citizens. Part III includes a list of national organizations concerned with one or more genetic disorders; some of them may have a chapter in your community. Contact these organizations for information about their programs and how to join.

Organizing A Group

Try to find two or three other concerned parents who can help you organize the group. You may know some people already. Local chapters of national organizations may be able to tell other families in your community who have members with genetic disorders about your idea and ask them to contact you if they would like to help.

Now What?

Once you have a small group of parents you can begin to work. The major jobs of the planning group are to answer some basic questions, to find parents who want to join a group, and to set up the first meeting.

What Kind Of Group?

You will need to decide if you want the group to be for parents of children who all have the same disease or for all parents who have a child with a genetic disorder. Some thoughts to consider:

Advantages Of A Group For A Single Disease:

- It can focus on the specific problems of the condition.
- It can develop specific solutions to these problems.
- A major organization that can help with resources might already exist for this condition.

Advantages Of A Group For A Range Of Genetic Conditions:

- Many problems faced by families with children who have genetic conditions are similar. Families can realize that their concerns are not unique or isolated.
- Parents of children with rare conditions are not left out.
- Broad-based groups are often more effective in working with health care agencies, schools, and the government.
- Parents can gain a better understanding of the wide range of genetic conditions.
- Several national organizations may have resources and solutions to share.

Should Health Professionals Be Invited To Join?

Health professionals can help you. They can bring parents together. They may be able to offer you a place to hold your first meeting. They can answer questions about medicine and health. They can advise the group. Professionals can be invited to participate as equal members of the group.

How Do You Reach Parents?

Tell people what you are doing and why. Contact your relatives and neighbors, pediatricians, school principals, and religious leaders. You may be surprised by the number of people who say "I know a family just like that" or "Maybe the Smiths might be interested."

Locate other parents to join you. Places to contact are:

- A local March of Dimes chapter.
- A local Association for Retarded Citizens, often listed in the telephone book under the name of your county, for example: Newton County Association for Retarded Citizens.
- Churches and synagogues.
- Board of Education - a staff member who is involved with special education programs.

- Children's hospitals.
- Local social service agencies.
- University medical centers.
- Local radio stations.
- PTA of your child's school.
- Visiting Nurse Association.
- Local newspaper.

Tell these people you are interested in locating other parents who might wish to join a support group. Briefly explain the purpose of the group. Ask for names and addresses of families who might be interested, or better yet, for mailing lists. If lists are confidential, ask if they will send letters for you. Enlist their ongoing support. Keep in touch with them as your plans develop.

When you have the names of some families, decide the best way to contact them. You might work through the person who gave you the name. Ask that person to contact the family to explain about your plan, and to invite a family member to call you.

Or you may want to contact families directly. A telephone call may upset a family who has recently experienced the birth of a child with a disorder. A sample letter, like the one on the next page, might be more effective. Be sure to include your telephone number. It is important to keep the names of families confidential.

Write a letter to the editor of your local newspaper. Discuss your organization and ask interested parents to contact you. A classified advertisement in the personal section of the newspaper has worked for some groups. A local radio station will probably make an announcement about the first meeting if you write out the information and mail it well in advance of the meeting date.

When And Where To Meet

Schedule the meeting for an evening or weekend so that working parents can attend. The first meeting can be held at your home, or a family doctor, local hospital, or community organization may be able to offer you a place to meet. Letters can be sent to families confirming the time and place of the first meeting.

SAMPLE LETTER

Dear Betty and Gene Smith:

Dr. Jones has suggested that we write to your family. We are interested in forming a group of parents with children with genetic disorders. This group will meet regularly to explore our feelings, share our problems and concerns, and learn more about how we can best care for our children and our families.

A meeting to discuss forming this group will be held at our home on March 15th at 7:30 p.m. Please call us at 985-3434 or 477-1212 for more information.

We hope that you can join us. We look forward to learning with you.

Sincerely,

James & Joanne Black
28 Oak Street
Anytown, Va. 22222

What Happens At The First Meeting?

- Ask people to introduce themselves and state why they have come. Members of the planning group should speak first. Explain your reasons for wanting to organize a parent group.
- "Brainstorm" possible activities for the group. Part II gives examples. Have each person state one thing they would like the group to do.
- Discuss simple guidelines that the group can follow:
  - — All members of the group should participate. "Talkers" should try not to take over conversations. Shy people should be drawn out. BUT no parent should ever be forced to take part in any discussion.
  - — The group doesn't need to elect officers. All that is needed is a person to coordinate meetings. The leader can change at each session.
  - — People should be honest.
  - — All members of the group should respect each other's beliefs, opinions, and actions.
  - — What people say at a meeting is confidential and should not be repeated outside the group.
  - — It is important to try to attend all meetings. Parents should tell one of the other members if they cannot come.
  - — Discuss plans for future meetings.
  - — Schedule meetings every week or every other week. Meetings should last about 2 hours.
  - — Arrange for meeting space at a clinic or office or hold meetings at a different family's house each time.
  - — If more than 12 people come to the first meeting, break into smaller groups. Self-help groups start out best when they have 8 to 12 people. You might decide to have meetings in a large group once a month.
- Distribute copies of this booklet.

For more information about self-help organizations, see:

SUPPORT SYSTEMS AND MUTUAL HELP
By Gerald Caplan and Marie Killelia
New York: Grune and Stratton, 1976

SELF-HELP IN THE HUMAN SERVICES
By Alan Gartner and Frank Reissman
San Francisco: Jossey-Bass, Inc.
Publishers, 1977

THE STRENGTH IN US
By Alfred Katz and Eugene Bender
New York: New Viewpoints, 1976

PART II

SUGGESTED GROUP ACTIVITIES

DISCUSSION GROUPS

In the beginning, your meetings will probably be discussion groups. The members will share thoughts, feelings, and problems with each other. It may help parents to know that they are not alone and that others are feeling the same way. These discussions will also help the group learn about each other and feel comfortable together.

Below are some suggested topics for discussion. Your group may have other ideas.

Family: How does this child affect our marriage? Do I feel extra strain in our marriage? How are my other children reacting? Do they understand the problems?

Friends: What should I tell my friends? Have some of my friends stopped calling? What can I do about this?

Raising Our Child: Should I treat this child differently? Why do I become so impatient sometimes? Am I being overprotective? What about discipline? How can I prepare for the future? What should I do to help myself if I know my child will die?

Relatives: Should I tell my family my child has a genetic disorder? What can I tell my parents, brothers, sisters, cousins? Can I pass this disorder onto another child?

Doctors: Is it difficult to talk about my child's problems to doctors and other health personnel? Do I understand what I have been told about my child's conditions? Am I satisfied with my child's health care? Do I know what to do if I don't feel comfortable with the treatment prescribed?

Feelings: How do I feel about having a child with a serious disease or mental or physical problem? Why do I sometimes feel angry or scared? Do I feel guilty?

Future Children: Do we want to have more children? What are the chances we will have another child with the same disorder? Would we be able to cope with another child? Can I find out before a child is born if it has a genetic disorder?

EDUCATION ACTIVITIES

The group will want to learn more about genetics and genetic disorders. Parents can help each other understand the risks of having another child with the same disease. As the group develops, it might conduct a program to educate others about the subject. Some ideas:

- Read a book on genetics and discuss it at a meeting. Two useful books written for the general public, which can be obtained from your library or a bookstore are:

  THE GENETIC CONNECTION
  By David Henden and Joan Marks
  New York: William Morrow and Co., Inc. 1978

  KNOW YOUR GENES
  By Aubrey Milunsky
  Boston: Houghton Mifflin Co. 1977
  (Available in paperback)

- Request educational materials from the organizations listed in Part III. Start a mini-library.
- Invite a genetic expert to talk with your group.
- Hold joint meetings with other parent groups or voluntary organizations on specific subjects. Invite speakers or show films.
- Sponsor meetings on genetics for your PTA, church or temple, or the general public.
- Learn the medical terms used by doctors such as recessive, dominant, multifactorial, chromosomal, etc. A medical dictionary or one of the above-suggested books would be helpful. Call your local library for help with specific words, if necessary.
- Hold educational sessions for doctors. Tell them about the goals of your group. Ask them to refer parents of their patients.

HEALTH CARE ACTIVITIES

The group can help parents find the best health care for their children. Parents often know what diet works best, what exercises help, and what to do at 3:00 a.m. when their child is awake and crying. Parents can share the ways they help their child and find out what works with other children. But, remember, what helps in one family may not work for another.

Parents need to be sure that their child has the best possible care. This means learning as much as they can about their child's disorder. It means understanding the condition and management that is prescribed. It means asking their doctor questions until their concerns are satisfied.

Parents can help each other develop confidence in dealing with health care personnel. The group can help people who find it difficult to talk to or question doctors. "Role play" a medical situation. Ask one person to act as the doctor and another to act as the parent. The doctor has just described a complicated medical procedure. What do you say?

The group can help parents find the best care available in their community. Members can recommend doctors and clinics who have been especially helpful. The group can keep a referral file of supportive and knowledgeable doctors.

Each member of your group should be encouraged to see a person who specializes in genetic counseling. These may be genetic counselors, nurses, social workers, or doctors with special training. Your doctor or local health department can refer you to someone for this service. They can help answer these questions:

- What is the cause of the disorder?
- What are the chances that future children will have the condition?
- Are there tests that can be done before birth to detect this disorder?

Before the counseling sessions, the group may want to work together to develop family histories, which counselors call pedigrees. List the first names and relationships of both parents' relatives. Include grandparents, parents, aunts, uncles, cousins, brothers, sisters, nieces, nephews, and your other children. Put an asterisk (*) next to anyone with a similar disorder, a birth defect, or other handicap. Put a check mark (✓) next to anyone who has died and state the cause of death. Share this list with the genetic counselor and your group. Do you see patterns? Some people may feel uneasy about sharing information about their family and may choose not to do this exercise.

Invite an expert in genetics to talk to your group. It is often very difficult to understand the risks involved in having another

child. It helps to have plenty of time to understand and ask questions.

Your group can also provide emotional support to its members. You can help each other explore feelings and fears about future childbearing. You can visit new parents of children with genetic disorders and help them cope with their initial feelings.

If parents in your group decide to have another child, encourage the woman to begin prenatal care early in pregnancy. Many genetic disorders can be detected before the birth of the child. A procedure called amniocentesis is used to test the fluid from around the fetus. A pregnant woman can find out if amniocentesis would be helpful to her. If the results of the tests reveal any problems, counseling may help parents decide what to do. The group can provide emotional support if a screening test detects a disorder.

There are tests for at least 60 diseases to identify people who may pass on certain harmful genes. These diseases include sickle cell anemia, Cooley's anemia, and Tay-Sachs disease. This identification is called genetic screening or genetic testing. If parents suspect a possible problem they can receive genetic counseling to learn their risks of having an affected child.

The Checklist for Genetic Counseling may help your friends and relatives determine if they have a higher risk of having a child with a disorder. One or more "yeses" means that the person should seek genetic counseling or testing. You may want to print this list so that you can pass it on to other families to answer for themselves.

Your group can make sure that genetic testing is available to people in your community. Call the local or State health department to find out what services are offered. Members can write letters or articles for the newspaper announcing these services. If they are not available, work with doctors, voluntary organizations, and the health department to get them started.

CHECKLIST FOR GENETIC COUNSELING

- Has anyone in your family had a child with a genetic disorder?
- Is there a family history of birth defects or mental retardation?
- Has the mother had three or more miscarriages?
- Is the mother over 35?
- Do more than three relatives on one side of the family have the same disorder?

ADVOCACY ACTIVITIES

An advocate is a person who causes or works for change. You are your child's best advocate. Parents can work together to be sure their child has the best life possible. You can work for changes to ensure your child's health care, special education, and ability to lead a full life.

Your group may decide to work together to assure the rights of all handicapped people. Work with other parent groups and voluntary organizations. Focus on a few areas instead of trying to do everything at once. Your efforts can be aimed at the national, State, or local level.

NATIONAL

- Public Law 94-142, the Education for all Handicapped Act, guarantees all children the right to a free, appropriate education. Every child with a handicap must have an Individualized Education Plan. This is a written plan that is developed jointly by your child's teacher, the school's special education teacher, an expert in evaluation of handicapped children, and you, the parents.
- Write for leaflets and fact sheets about your child's right to education from:

  BUREAU OF EDUCATION FOR THE HANDICAPPED
  U.S. Office of Education
  Washington, D. C. 20202

- Contact:

  CLOSER LOOK
  Parent's Campaign for Handicapped Children and Youth
  Box 1492
  Washington, D.C. 20013

This agency can supply needed information, such as how to locate an organization in your community that specializes in education for the handicapped; your child's right to education under Federal law; vocational education available for your child; and what testing and evaluation procedures should be used to determine your child's abilities.

- When you have a concern about national issues, write your Member of Congress. Keep your letters short, to the point, and ask for an answer. If you don't know the name of your Member of Congress, call the newspaper, library, or local government office.

- Every Representative and Senator is eager to help you with your problem. If you are having difficulty finding quality health services or not getting proper education for your child, write:

  The Honorable Congressman
  U.S. House of Representatives
  Washington, D.C. 20515

  or

  The Honorable Senator
  U.S. Senate
  Washington, D.C. 20510

- Support national organizations that are interested in the handicapped.

STATE

- Find other groups that are working for the rights of the handicapped in your State. Offer your help. Contact your State representative. Call the mayor's office or other public officials to find out who it is.
- Find out who chairs the health and education committees in the State legislature. Meet with them.
- Contact the State Office of Education. Invite someone to speak to your group about State special education laws.
- Check out State programs. Is there newborn screening for metabolic disorders? Does the State have laws protecting the rights of the handicapped? What new laws are being introduced?

LOCAL

- Go to local government meetings. Ask your representative to describe pending bills about the handicapped.
- Contact the person in charge of special education at your local board of education.
- Run for office on the local school board or town council.
- Ask the mayor to meet with your group to hear your concerns.
- Write articles or letters to your newspaper on the rights of the handicapped, the need for genetic screening and services in your community.

These are only suggestions for possible activities. Let your group think up other ideas. There is a lot of work to be done.

If you form a parent's group by using this booklet, we would like to know. Please write the Genetic Disease Services Program PHS/HSA/BCHS, 5600 Fishers Lane, Rockville, Maryland 20857 and tell us about your activities.

PART III

RESOURCES TO HELP YOU

FEDERAL GOVERNMENT

Genetic Disease Services Program

The Department of Health, Education, and Welfare has a Genetic Disease Services Program which funds genetic testing and counseling programs in 21 States. These are:

Alabama
Colorado
Connecticut
Florida
Georgia
Iowa
Maine
Michigan
Nebraska
New Jersey
New York
Ohio
Pennsylvania
Rhode Island
Tennessee
Texas
Vermont
Virginia
Washington
Wisconsin
West Virginia

Other States also have genetic programs. Call your State health department for more information about the services offered in your community.

The Federal Genetic Disease Services Program established a National Clearinghouse for Human Genetic Diseases in 1978. It will help you find information about your child's specific genetic condition and assist you in locating other parent groups. You can write to:

NATIONAL CLEARINGHOUSE FOR HUMAN GENETIC DISEASES
1776 East Jefferson Street
Rockville, Maryland 20852
301-279-4642

(Additional copies of this booklet are available without charge from the Clearinghouse.)

Services For Crippled Children

Since 1935, the Federal Government has been providing grants to each State for a crippled children's agency, usually located in the State department of health. Its purposes are:

- To locate handicapped children.
- To diagnose their condition.

- To advise parents on treatment for their child.
- To help parents find good health care for their child.
- To help parents with financial planning.
- To pay for some or all of the medical care for children in families with low incomes.

Each State has its own law defining the conditions that can be treated by the crippled children's agency. In most States, children under the age of 21 are eligible if they have:

- A handicap requiring orthopedic or plastic treatment, such as cleft lip, cleft palate, club foot, paralyzed muscles and cerebral palsy.
- Heart disease.
- Epilepsy.
- Cystic fibrosis.
- Vision problems that need surgery.
- Hearing problems.

Some States have broader programs that deal with children who have multiple handicaps or who are mentally retarded. Call your State health department for the address and telephone number of the crippled children's agency. Contact them for information about services available to your child.

Supplemental Security Income

If your child is younger than age 7 and your family has a very small income, you may be eligible for Supplemental Security Income benefits. Call the Social Security Administration (SSA) office in your community for the Disability Determination Service at the District SSA office.

Clearinghouse On The Handicapped

The Clearinghouse on the Handicapped will also be able to assist your family and parent group. It publishes a directory of organizations and can help find other sources of information and assistance. You can write to:

CLEARINGHOUSE ON THE HANDICAPPED
Room 338D - Hubert Humphrey Building
Washington, D.C. 20202
202-245-1961

For more information about Federal Programs in your area, contact the Division of Health Services Delivery in the DHEW Regional Office closest to you.

Region I
John F. Kennedy
Federal Building
Boston, Mass. 02203
617-223-6827

Region II
26 Federal Plaza
New York, N.Y. 10007
212-264-2560

Region III
P.O. Box 13716
Philadelphia, Pa. 19101
303-837-4461

Region IV
101 Marietta Towers
Atlanta, Ga. 30323
404-221-2316

Region V
300 S. Wacker Drive
Chicago, Ill. 60606
312-353-1385

Region VI
1200 Main Tower Building
Dallas, Texas 75202
214-655-3879

Region VII
601 East 12th Street
Kansas City, Mo. 65106
816-374-3291

Region VIII
19th and Stout Streets
Denver, Col. 80202
303-837-4461

Region IX
50 United Nations Plaza
San Francisco, Cal. 94102
206-442-0438

Region X
1321 Second Avenue
Seattle, Wash. 98101
206-442-0438

ORGANIZATIONS

Many organizations may be able to help you by providing speakers, education materials, financial assistance, and tips on how to locate other parents, and more information. You may want to work with them. Below is a partial list of national organizations. Organizations that deal with many handicaps are listed under "General." Organizations that concern a specific genetic disorder are listed under that disease. Inclusion in this list is not an endorsement of an organization or its activities by the Department of Health, Education, and Welfare. For more information about an organization's activities and chapters in your community, write to the given address. Tell them you are forming a parent group. It is a good idea to enclose a self-addressed stamped envelope.

General Organizations

COMMITTEE FOR THE HANDICAPPED
1028 Connecticut Avenue, N.W. 610
Washington, D.C. 20036

This committee publishes "The Directory of Organizations Interested in the Handicapped"; it lists national organizations dealing with a wide range of handicaps.

COUNCIL FOR EXCEPTIONAL CHILDREN
1920 Association Drive
Reston, Virginia 22091

This organization has information on many types of handicaps. They have useful information about raising and teaching your child.

NATIONAL ASSOCIATION OF RETARDED CITIZENS (NARC)
2709 Avenue E. East
P.O. Box 6109
Arlington, Texas 76011

NARC has over 300 local chapters. Look up the name of your county followed by ARC in your telephone book or, write the national headquarters for the address of the closest chapter. They have a catalog of their publications.

THE NATIONAL EASTER SEAL SOCIETY FOR CRIPPLED CHILDREN AND ADULTS
2023 West Odgen Avenue
Chicago, Illinois 60612

The Easter Seal Society deals with all types of physical handicaps. It produces a journal, bibliographies, and many publications. Write for a copy of their publications list.

MARCH OF DIMES BIRTH DEFECTS FOUNDATION
1275 Mamaroneck Avenue
White Plains, N.Y. 10605

The March of Dimes has 11,000 local units. This organization is concerned with the prevention of all birth defects. The local unit is a good place to locate other parents. Write the national organization for publications. "Birth Defects - The Tragedy and the Hope" and "Genetic Counseling" are free and good reading. Mention a specific disorder if you are interested in one condition.

NATIONAL GENETICS FOUNDATION
9 West 57th Street
New York, N.Y. 10019

This organization promotes a genetic counseling network. The staff knows about genetic counseling and treatment centers. They can put you in touch with specialists and genetic counselors. Write for their brochures "How Genetic Disease Can Affect You and Your Family" and "Can Genetic Counseling Help You?"

NATIONAL SELF-HELP CLEARINGHOUSE
184 Fifth Avenue
New York, N.Y. 10010

Write the clearinghouse for the names of parent groups in your community. If you form a group, let them know so they can put people in touch with you.

PARENTING MATERIALS INFORMATION CENTER
Southwest Education Development Laboratories
2ll East 7th Street
Austin, Texas 78701

They will send you booklets on how to be a good parent. They have special materials on raising a handicapped child.

Organizations For Specific Conditions

Cleft Lip and Cleft Palate

- **CLEFT PARENT GROUP**
  P.O. Box 6215
  San Jose, California 95150

- **PRESCRIPTION PARENTS**
  P.O. Box 855
  Quincy, Massachusetts 02169

Cooley's Anemia (also called Thalessemia)

- **COOLEY'S ANEMIA BLOOD AND RESEARCH FOUNDATION**
  Graybar Building. Suite 1644
  420 Lexington Avenue
  New York, N.Y. 10017

Cystic Fibrosis

- **CYSTIC FIBROSIS FOUNDATION**
  3379 Peachtree Road, N.E.
  Atlanta, Georgia 30326

Down's Syndrome (also known as Trisomy 21)

- **DOWN'S SYNDROME CONGRESS**
  P.O. Box 1527
  Brownwood, Texas 76801
- **NATIONAL ASSOCIATION FOR DOWN'S SYNDROME**
  P.O. Box 35268
  Houston, Texas 77035

Dysautonomia

- **DYSAUTONOMIA FOUNDATION**
  370 Lexington Avenue
  New York, N.Y. 10017
- **NATIONAL FOUNDATION FOR JEWISH GENETIC DISEASES**
  608 Fifth Avenue, Room 702
  New York, N.Y. 10020

Hemophilia

- **NATIONAL HEMOPHILIA FOUNDATION**
  25 West 39th Street
  New York, N.Y. 10018

Huntington's Disease

- **COMMITTEE TO COMBAT HUNTINGTON'S DISEASE, INC.**
  250 W. 57th Street
  New York, N.Y. 10019

- **HEREDITARY DISEASE FOUNDATION**
  9701 Wilshire Boulevard
  Beverly Hills, California 90212
- **NATIONAL HUNTINGTON'S DISEASE ASSOCIATION**
  Suite 501
  1441 Broadway
  New York, New York 10018
- **THE WILLS FOUNDATION**
  P.O. Box 66704
  Houston, Texas 77006

Mucopolysaccharidosis (MPS), Mucolipidosis (MLS)

- **MUCOPOLYSACCHARIDOSIS SOCIETY, INC.**
  522 Central Avenue
  Bethpage, N.Y. 11741

Muscular Dystrophy

- **MUSCULAR DYSTROPHY ASSOCIATION**
  810 Seventh Avenue
  New York, N Y. 10019

Neurofibromatosis

- **NATIONAL NEUROFIBROMATOSIS FOUNDATION**
  340 E. Eightieth Street
  New York, N.Y. 10021

Phenylketonuria (PKU)

- **PKU PARENTS GROUP**
  518 Paco Drive
  Los Altos, California 94022
- **THE PKU CLINIC**
  Children's Memorial Hospital
  2300 Children's Plaza
  Chicago, Illinois 60614

Retinitis Pigmentosa

- **NATIONAL RETINITIS PIGMENTOSA FOUNDATION**
  8331 Mindale Circle
  Baltimore, Maryland 21207

Sickle Cell Anemia

- **NATIONAL ASSOCIATION OF SICKLE CELL CLINICS**
  1425 Old Country Road
  Plainview, N.Y. 11803
- **NATIONAL ASSOCIATION OF SICKLE CELL DISEASE, INC.**
  945 South Western Avenue
  Los Angeles, California 90006

Spina Bifida

- **SPINA BIFIDA ASSOCIATION OF AMERICA**
  343 South Dearborn, Room 319
  Chicago, Illinios 60604

Tay-Sachs

- **NATIONAL TAY-SACHS AND ALLIED DISEASES ASSOCIATION**
  122 East 42nd Street
  New York, N.Y. 10017
- **TAY-SACHS PREVENTION PROGRAM**
  200 Trapelo Road
  Waltham, Massachusetts 02154

Also write *NATIONAL FOUNDATION FOR JEWISH GENETIC DISEASES*. See Dysautonomia.

Tourette Syndrome

- **TOURETTE SYNDROME ASSOCIATION**
  Bell Plaza Building
  42-40 Bell Boulevard
  Bayside, N.Y. 11361

Tuberous Sclerosis

- **TUBEROUS SCLEROSIS ASSOCIATION OF AMERICA**
  P.O. Box 44
  Rockland, Massachusetts 02370